ask an Expert: contributors

Nicole Goetz, MS, APRN-BC
earned her undergraduate and graduate degrees in Nursing as a Family Nurse Practitioner at Pace University. She is currently pursuing a Doctorate of Nursing Practice at the University of New Jersey.

After completing her training, Ms. Goetz served as the coordinator of health services at Ramapo College of New Jersey, where she was an adjunct faculty member. Following her work in this academic setting, Ms. Goetz was engaged as a family health nurse practitioner at Immedicenter, where she provided primary and emergency healthcare services. At the same time, she served as a clinical preceptor for Ramapo University’s Nurse Practitioner Program. Ms. Goetz relocated to New York, where she worked at Rockland Pulmonary and Medical Associates, providing both primary and emergency care to her patients.

Currently, Ms. Goetz is a nurse practitioner in the Division of Upper GI and Endocrine Surgery at Columbia University Medical Center—New York Presbyterian Hospital. She manages patients’ surgical experiences, and conducts pre-op, post-op, episodic, emergent, and routine follow-up office visits. Ms. Goetz is also an assistant clinical professor of nursing at Columbia University.

Virginia Goetz (VC): Let’s begin with the hospital experience. What can patients expect in hospital recovery to be like after pancreatic surgery?

Nicole Goetz (NG): After pancreatoduodenectomy and other major operations on the pancreas, patients can expect to be in the hospital anywhere from five days to three weeks, depending upon the type of surgery performed. In general, an average hospital stay is seven to ten days. Most patients can expect a stint in ICU, or an extended stay in the recovery room (meaning overnight). Even though they will be hydrated with intravenous (IV) fluids, patients won’t be eating solid food just yet. They will be maintained on intravenous (IV) fluids until just before they go home (or for at least five to seven days from surgery). Most patients are out of bed within two days. We try to get patients ambulating as soon as possible. VC: I would imagine that the recovery process doesn’t always progress as hoped. What kinds of medical complications can occur while in the hospital?

NG: Because the pancreas is a gland, one of the most common complications with pancreas surgery is a pancreatic leak. In order to determine if there is a leak, a surgeon will usually instill something called a Jackson-Pratt (JP) Drain. If there is a leak, treatment may involve leaving the drain in longer than we’d typically like to. Only on rare occasions will we have to operate for a leak.

Another type of complication is called delayed gastric emptying. Because there’s a new connection between the stomach and the small bowel, food and bodily fluids like bile and saliva can run in the stomach for prolonged periods of time, delaying emptying into the small bowel and throughout the rest of the GI tract. This can cause nausea and vomiting for some patients, and if they are unable to eat for prolonged periods of time they may have to be fed intravenously. Managing Total Parenteral Nutrition (TPN). The intention is usually short-lasting, meaning it resolves itself in about six weeks. Of course, six weeks can feel like an eternity to a patient.

Other common complications can include infected abdominal wound infections, complications such as wound infections, deep venous thrombosis (DVT), pneumonia, uterine tract infection and other infections. Although pain can be an issue, it is usually controlled well with intravenous pain medication.

VC: Eventually, patients leave the safety of the hospital. As much as we hate being in a hospital, it usually feels like a safe place to be after a major operation. What kinds of issues can arise after discharge, and how can those affect one’s willingness to “get back into life?”

NG: Most patients are anxious to get out of the hospital. They’re eager to be back in the hospital to treat any fluid like they feel like a very long time, and they want to go home. Once they arrive home, however, they may start to feel overwhelmed. Family members may also start to feel overwhelmed, especially those who are preparing to serve as primary caregivers. Some patients will have a visiting nurse, but the nurse is not with them every day, or even for the whole day. So, it can be scary to both patients and family to be home.

At the time of discharge, patients usually only a day’s worth of meals in them. Often, this is not enough to be acquainted with their new digestive tract. Patients require assistance to comply with their dietary tract and other infections. Although pain can be an issue, it is usually controlled well with intravenous pain medication.

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Words in bold are defined in the glossary.
“Managing your new life after pancreatic surgery”

NG: At Columbia, we provide patients with pre-operative counseling, which includes a consultation with a surgeon and nurse. Nutritionalists are also available to speak with patients in the hospital. I also walk patients and family members through what to expect after discharge. We find it is helpful to have the surgeon and/or nurse with any questions. For example, if a patient develops a wound infection, or returns home with tubes or drains for feeding, this might quality them for a visit. Often times, however, patients’ medical needs do not warrant the services of a visiting nurse, and we will instead arrange for outpatient community services, such as physical therapy to help a patient gain strength and improve appetite. Geriatric and/or inpatient nurses who undergo pancreatic surgery usually require a rehabilitation stay to a rehabilitation facility, or some type of skilled nursing facility, upon discharge from the hospital and before they can safely return home.

VC: In terms of follow-up, is there any particular kind of in-home care that families should be prepared to deliver, or that the patient needs to consider, after pancreatic surgery?

NG: During discharge planning, hospital social workers serve as case managers, arranging for follow-up services. One excellent alternative resource is a visit from a visiting nurse. Visiting nurses can be arranged if the patient meets certain criteria, which is determined through a nursing assessment. For example, if a patient develops a wound infection, or returns home with tubes or drains for feeding, this might quality them for a visit. Often times, however, patients’ medical needs do not warrant the services of a visiting nurse, and we will instead arrange for outpatient community services, such as physical therapy to help a patient gain strength and improve appetite. Geriatric and/or inpatient nurses who undergo pancreatic surgery usually require a rehabilitation stay to a rehabilitation facility, or some type of skilled nursing facility, upon discharge from the hospital and before they can safely return home.

VC: What about medical follow-up? For how long does the surgical team care for patients after they leave the hospital?

NG: It depends on the individual medical needs of the patient. But typically, if a patient is discharged after a one-week stay, they may have to return to have tubes or drains removed, and this can usually be done on an outpatient basis. Otherwise, patients typically return to the surgical office at about the two-week mark to have blood work, receive a weight check, evaluate their incision site, and receive a basic physical exam. The surgical team will have arranged that the patient follow-up visit at discharge, and patients are given explicit instructions for the initial post-operative follow-up visit. The next visit is usually another two weeks later.

VC: Is there a typical appointment schedule for patients that by the time they go home, or not they are surgical candidates when they go home. Although we try to make sure patients can tolerate food and digest it comfortably, they leave the hospital if the patient is still patients that by the time they go home, they’re going to be eating normally a quarter of what they normally eat. Appetites is significantly affected by the surgery. Patients are encouraged to have a healthy weight before surgery. Many patients lead active lives, and they want to know that they can do those things that make them happy – whether it’s working out at the gym, playing golf, or visiting with friends – they want to resume a normal level of activity.

VC: What would you describe as “top patient concerns” following surgery?

NG: I think the biggest concerns are nutrition and diet, because as we mentioned earlier, patients are not eating much before and after surgery. Although we try to make sure patients can tolerate food and digest it comfortably, they leave the hospital if the patient is still patients that by the time they go home, they’re going to be eating normally a quarter of what they normally eat. Appetites is significantly affected by the surgery. Patients are encouraged to have a healthy weight before surgery. Many patients lead active lives, and they want to know that they can do those things that make them happy – whether it’s working out at the gym, playing golf, or visiting with friends – they want to resume a normal level of activity.

VC: Much depends on the individual and the type of surgery. It’s unbelievable to me how quickly and completely some patients are able to bounce back after pancreatic surgery, with little change to their lifestyle. But most patients may struggle to find a “new normal.” Especially for patients who undergo neoadjuvant therapy, this can be challenging. These folks really must immediately learn to manage pancreatic insufficiency (enzyme dependency) and insulin-dependent diabetes. In my experience, the best way to prepare an individual for their “new life” after surgery is to strike the notion of “new normal” in a candid discussion before surgery.

“Encourage patients to consider joining a community-based diabetes support group, because managing diabetes is one of the biggest lifestyle adjustments for post-pancreatic surgery patients. Web-based support groups are also a great option, because the nature and duration of recovery from this kind of surgery can sometimes make it difficult for patients to get out of the house.”

“If not, you may want to consider joining a community-based diabetes support group, because managing diabetes is one of the biggest lifestyle adjustments for post-pancreatic surgery patients. Web-based support groups are also a great option, because the nature and duration of recovery from this kind of surgery can sometimes make it difficult for patients to get out of the house.”

“For many patients, recovery includes striving to find a ‘new normal.’”

MOCA (Multicenter Autoimmune Colitis Study) - A Randomized Controlled Trial of Infliximab for Autoimmune Colitis

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“Managing your new life after surgery”

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“For most patients, recovery includes striving to find a “new normal.”

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Sometimes, you can’t know the extent of lifestyle and medical complications until after surgery, and this can be difficult for patients. It’s important to prepare patients for a two to three-month recovery process, as well as the possibility of adjuvant treatments.

Some lifestyle changes may have to be permanent; some patients can never again consume oily or greasy foods without having to deal with digestive concerns immediately afterward. Patients should discuss their dietary needs and any changes in their health care provider. Together, they may be able to develop “tricks” to help them cope with lifestyle changes.

We know that no matter how successful the surgery, there is always a chance of recurrence. When this occurs, patients in the case of recurrence, and how can patients learn more?

There are several options available to post-surgical patients who face a recurrence of pancreatic cancer. Radiofrequency Ablation (RFA), conducted by an interventional radiologist, may be an option if the tumor is localized. Radiofrequency ablation involves using a probe to “heat” an isolated tumor. Radiotherapy (ex. CyberKnife®) is a very targeted form of radiation that “narrow” the potential pool of survivors. Unfortunately, because the occurrence of pancreatic cancer is not common, and because the overall five-year survival rate is not as high as many other cancers, there aren't as many support groups in general. If a patient is learning difficulty locating a support group, I would suggest speaking with the social worker or nurse from the surgical team, or the community medical oncology, to inquire about local support services. I sometimes encourage patients who have undergone a total pancreatectomy to join a diabetes support group, because they are easier to find and become an in-person support group.

If a patient is having difficulty locating a support group? Are there advantages to Web-based support groups for individuals who have undergone pancreatic surgery?

A listing of in-person support groups.

The Wellness Community

PanCAN offers a Survivor and Caregiver Network and a listing of in-person support groups.

Michael Rolfe Pancreatic Cancer Foundation

Supports pancreatic cancer support groups in Illinois.

PanCancerCare

(888) 793-WELL (9355)

The Wellness Community

1-800-707-WELL (9355)

http://www.thewellnesscommunity.org/support

Offers internet-based support group for pancreatic care

Adenocarcinoma – Cancer that begins in the cells lining internal organs and that has gland-like (secretory) properties

Adjuvant Therapy – Treatment given after the primary treatment to increase the chances of a cure. Adjuvant therapy may include chemotherapy, radiation therapy, hormone therapy, or biological therapy

Mucinous pancreatic cyst adenoma – A slow-growing mass of cells that may resemble a cyst, but can also be made up of adenomatous tissue

Intraductal Papillary Mucinous Neoplasms (IPMN) – Simple cysts, polyps or tumors that are connected to the duct system in the pancreas so that the secretions do not drain properly

Pancreatic Insufficiency – Not enough of the digestive enzymes normally secreted by the pancreas into the intestinal tract

Pancreatic Inflammation – Any type of inflammation that can cause swelling in the pancreas. Pancreatitis is also the term used to describe the inflammation of the pancreas

Pancreatic Lipoma – A benign tumor that occurs in the pancreas

Recurrent Treatment – Treatment given after surgery for a recurrence of the cancer

Secondary Neoplasms – A second cancer that forms in tissue where normal cells have been replaced by abnormal cells

Surgical Treatment – Treatment given to remove the cancer

Additional Resources

The Pancreas Center at Columbia University!

New York-Presbyterian Hospital/Weill Cornell Medicine

www.pancreascenter.org

CancerCare

1-800-813-4004 (607)

www.cancercare.org

Offers telephone - and internet-based support groups for pancreatic cancer patients and caregivers.

Joint Commission on Accreditation of Healthcare Organizations (JCAHO)

http://pathology.jhu.edu/WEB/JP=68&L=Pancreas_CHAT

(See Resource Box)

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What about internet-based support groups? Are there advantages to Web-based support groups for individuals who have undergone pancreatic surgery?

According to ACS, an estimated 37,700 people were diagnosed with pancreatic cancer in 2017.

Expert-Managing your new life after surgery

Sometimes, you can’t know the extent of lifestyle and medical complications until after surgery, and this can be difficult for patients. It’s important to prepare patients for a two to three-month recovery process, as well as the possibility of adjuvant treatments.

Some lifestyle changes may have to be permanent; some patients can never again consume oily or greasy foods without having to deal with digestive concerns immediately afterward. Patients should discuss their dietary needs and any changes in their health care provider. Together, they may be able to develop “tricks” to help them cope with lifestyle changes.

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**Glossary**

**Adenocarcinoma** – Cancer that begins in cells that line internal organs and that have gland-like (secretory) properties.

**Adjuvant Therapy** – Treatment given after the primary treatment to increase the chances of a cure. Adjuvant therapy may include chemotherapy, radiation therapy, hormone therapy, or biological therapy.

**Deep Venous Thrombosis** – A type of blood vessel condition in which a blood clot forms in a vein. It can be genetic or caused by injury or certain medications.

**Intravenous Feedings** – A type of external radiation therapy that can cause damage to healthy tissue. It is also being studied to treat pancreatic cancer.

**Radiofrequency Ablation** – A type of external radiation therapy that can cause damage to healthy tissue. It is also being studied to treat pancreatic cancer.

**Total Parenteral Nutrition** – A way for a person’s body to receive nutrients through the veins, bypassing the digestive system.

**Pancreatic Insufficiency** – Not enough of the digestive enzymes normally secreted by the pancreas into the intestine.
Although I lost both my mother and daughter to pancreatic cancer and was myself diagnosed with chronic pancreatitis, I did not dwell on the possibility that I would develop this feared disease. I was seeing a trusted gastroenterologist (GI) on a regular basis and had confidence in him. So it came as a real shock when my GI doctor explained that the pancreatic cysts he had been watching for years were starting to show signs of turning cancerous.

As he said, I visited the multidisciplinary Pancreatic Cancer Clinic at Johns Hopkins, where much early detection research is being conducted. There, I met Dr. Marcia Canto and learned about her Early Detection Screening Study. On March 30, 2007, I made the difficult decision to undergo the procedure. That said, the first week in aftercare was by far the most difficult. A pain pump and other pain medications helped, and although it wasn’t easy, I was able to get out of bed and walk a little each day.

I was glad I thought to bring some of the comforts of home with me to the hospital, including my favorite pillow. I was a little bring a sleeping pill because the hospital staff doesn’t maintain it as one of their own. Also, a comfortable pair of slippers are important, and I took both a warm pillowcase so the hospital staff doesn’t mistake it as one of their own. A warm and cool robe is important, and I took both with me to cope with changing temperatures.

The date of my surgery was the birthday of our daughter, Debbie, who succumbed to pancreatic cancer at 37. At first, the thought of undergoing pancreatic surgery on this date made me nervous; in retrospect, I think it was a good omen, which has grown this new meaning to the difficult date.

I received wonderful care from the surgeon, gastroenterologist, and all of the staff at Johns Hopkins. I knew I had made the right decision to have the surgery. That said, the first week in aftercare was by far the most difficult. A pain pump and other pain medications helped, and although it wasn’t easy, I was able to get out of bed and walk a little each day.

I had read that people lose a good bit of weight after this surgery, and was actually looking forward to some weight loss. But the first time I stepped on the hospital scale, I had actually gained weight. I quickly realized that the extra weight was fluid retention (a by-product of the surgery). I was glad that I had kept my jewelry at home, since my medical finger may have caused problems. After a couple of days, the fluid weight dropped, and I continued losing weight.

Now ten months later, I have kept the weight off (25 pounds) and have even lost a few pounds more. I stepped on the hospital scale, I had actually gained weight! I quickly realized that the extra weight was fluid retention (a by-product of the surgery). I was glad that I had kept my jewelry at home, since my medical finger might have caused problems. After a couple of days, the fluid weight dropped, and I continued losing weight.

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I had read that people lose a good bit of weight after this surgery, and was actually looking forward to some weight loss. But the first time I stepped on the hospital scale, I had actually gained weight! I quickly realized that the extra weight was fluid retention (a by-product of the surgery). I was glad that I had left my jewelry at home, since my metal ring would have caused problems. After a couple of days, the fluid weight dropped, and I continued losing weight. Now, six months later, I have kept the weight off 15 pounds and have even lost a few pounds more. For me, this is an achievement, and for the first time in my life, my dentist has asked me not to lose more weight! However, I do appreciate the concerto that this kind of weight loss can cause for someone who is already thin before surgery.

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My appetite in the hospital was poor, and to date, I rarely feel hungry. Food tasted odd at the beginning; some days everything I ate tasted like pepper had been ground over it, and for a few days, a taste of burned poppy seeds lingered in my mouth. My advice: Don’t be alarmed, as these symptoms will pass. Today, most food tastes about the same as it did before, although some foods still lack taste. I think each patient has to maneuver her “new stomach” following surgery.

At ten months post-surgery, I can honestly say that I feel great, and I have no regrets. Even with diabetes, I can do everything I used to. Although I lost both my mother and 37-year-old daughter to pancreatic cancer, and was myself diagnosed with chronic pancreatitis, I did not dwell on the possibility that I would develop this feared disease. I was seeing a trusted gastroenterologist (GI) on a regular basis and had confidence in him. So it came as a real shock when my GI doctor explained that the pancreatic cysts he had been watching for years were starting to show signs of turning cancerous.

As he was saying, I visited the multi-disciplinary Pancreatic Cancer Clinic at Johns Hopkins, where much early detection research is being conducted. There, I met Dr. Marcia Canto and learned about her Early Detection Screening Study. On March 30, 2007, I made the difficult decision to undergo a total pancreatectomy, which included the removal of my gallbladder and duodenum. Fortunately, my surgeon was able to spare my spleen. And duodenum. Fortunately, my surgeon was able to spare my spleen.
Managing your new life after surgery

Nicole Goetz, MS, APRN-BC

Let’s begin with the hospital experience. What can patients expect in hospital recovery to be like after pancreatic surgery?

Nicole Goetz (NG): After pancreatic surgery and other major operations on the pancreas, patients can expect to be in the hospital for anywhere from five days to two weeks, depending upon the type of surgery performed. In general, an average hospital stay is seven to ten days. Most patients can expect to be able to go home in about five to seven days from surgery (or for at least five to seven days from surgery).

Another type of complication is called delayed gastric emptying. Because there’s a new connection between the stomach and the small bowel, food and liquid fluids like milk and sugar can’t be absorbed in the small bowel as quickly as they normally would. This can slow down the emptying of food into the small bowel and throughout the rest of the GI tract. This can cause nausea and vomiting for some patients, and if they are unable to eat for prolonged periods of time they may have to be fed intravenously. The American Pancreatic Association recommends Total Parenteral Nutrition (TPN). The intention is usually short-term, meaning that it resolves itself in about six weeks. Of course, six weeks can feel like an eternity to a patient.

NG: Sometimes patients will have to be readmitted for what feels like a very long time.

VC: Eventually, patients leave the safety of the hospital. As much as we hate leaving a hospital, it usually feels like a safe place to be after a major operation. What kinds of issues can arise after discharge, and how can these affect one’s willingness to “get back into life?”

NG: Most patients are anxious to get out of the hospital. They’ve been in this hospital for what feels like a very long time, and they want to go home. Once they arrive home, however, they may start to feel overwhelmed. Family members may also start to feel overwhelmed, especially those who are preparing to serve as primary caregivers. Some patients will have a visiting nurse, but the nurse is not with them every day, or even for the whole day. So, it can be scary to both patients and family to be home.

At the time of discharge, patients usually only get a week of meals in them. Often, this is not enough to be acquainted with the “new” digestive tract. Patients often experience vomiting upon their return home. This doesn’t speak to the success of the surgery, just to the return of normal epithelial function in the small bowel and stomach. A small percentage of patients will have to be readmitted for...